ERIC Document Resume | See Instruction Sheet | DATE OF RESUME | DATE RECEIVED

A. PUBLICATION DATA

1. ERIC NUMBER: ED002201 | 2. ORIGINATOR CONTROL NO(S).: N.A. | 3. IDENTIFICATION NO.: N.A. | DO NOT WRITE IN SPACE BELOW

4. AUTHOR(S): Oettinger, Katherine B.

5. TITLE OF DOCUMENT ABSTRACTED: The Disadvantaged Children and Youth of America

6. PUBLICATION TITLE: N.A.

7. EDITOR(S): N.A.

8. PLACE OF ORIGIN: ORG. U.S. Department of Health, Education, and Welfare; ST.; CITY, STATE Washington, D.C.; TELE. EXT.; INST/LOC CODE

9. PUBLISHER OR SOURCE: U.S. Department of Health, Education, and Welfare Washington, D.C.

10. VOL.	11. PAGES	12. MO./YR.	13. TOTAL PP.
N.A.	N.A.	N.A.	16

MICROFILM COPY AVAILABLE: YES ☒ NO ☐

COPYRIGHT GRANTED: YES ☐ NO ☒

COPYRIGHT RELEASE FILED: YES ☐ NO ☐

TYPE OF REPORT: PROPOSAL ☐ IN-PROGRESS ☐ FINAL ☒ FOLLOW-UP ☐

OTHER ERIC REFERENCES:

ERIC SATELLITE CODE

B. INDEXING DATA

14. SUBJECT AREA

15. TYPE OF ENDEAVOR: Speech

16. INDEXING TERMS (6-12)

disadvantaged children
mental retardation
retarded child
socioeconomic factors
physical handicapped
health programs

17. ABSTRACT (MAX. 250 WORDS)

Progress is being made toward erasing the disadvantages of the mentally retarded. Much progress has been made in recognizing the health needs of the retarded child through substantial legislation sponsored by many branches of government, action programs stemming from both public and voluntary sources, and a mounting research effort.

In an effort to get at causation of mental retardation, the 1963 Maternal and Child Health and Mental Retardation Planning Amendments authorized grants as well as an appropriation, administered by the Children's Bureau, to help State and local health departments provide programs of comprehensive maternity and infant care for women.

The Children's Bureau through its partnership with the States is working toward the recognition of all the needs of the child in a program of child welfare services. It is trying to make the whole spectrum of child welfare services available to the child in his home in order to determine whether the child's problem is mental retardation or cultural deprivation. The Bureau is also encouraging institutions of higher learning and other nonprofit organizations to undertake pr jects which may add new dimensions to the kinds of services which could be provided in the forseeable future.

Many of the accelerated programs of the Bureau are discussed. The Bureau is also interested in health and welfare beyond the national borders and has developed a research program to this extent.

ERIC No.

18. SOURCE OF ABSTRACT

C. FUNDING DATA

19. SUPPORTING ORGANIZATION

20. DIVISION OR DEPT.

21. CONTRACT NO.

PROJECT NO.

22. TOTAL COST OF PROJECT

23. DURATION OR PROJECT

U.S. Department of Health, Education, and Welfare
Office of Education

ED002201

THE DISADVANTAGED CHILDREN AND YOUTH OF AMERICA

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U. S. DEPARTMENT of HEALTH, EDUCATION, and WELFARE — WELFARE ADMINISTRATION — Children's Bureau

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THE DISADVANTAGED CHILDREN AND YOUTH OF AMERICA*

by

Mrs. Katherine B. Oettinger
Chief, Children's Bureau

There is no point in our history when there has been greater determination that no child shall be disadvantaged. The climate has never been more auspicious for rapid progress in the fields of health and welfare.

We have reached that moment best described by Victor Hugo when he said, "Greater than the tread of armies is an idea whose time has come." Our determination to rid children of disadvantage is reaching out in a host of directions.

Poverty, that spectre which so saps the strength and purpose of those caught up in it, can and must be eliminated. Not only has the Administration repeatedly expressed determination to accomplish this, but economists tell us, as a Nation, we are ready for this achievement.

The United States currently has a gross national product which is one-fourth of the entire world total gross national product. In addition, since 1953, 60 percent of the increase of the world's

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* Address before the American Association on Mental Deficiency, Miami, Florida, June 8, 1965.

gross product has been achieved by the United States.

The anti-poverty war which already has been launched is fomenting self-examination among our leaders in the cities and rural areas--a self-examination which is leading to a new definition of "community" as representing all citizens.

It has become basic to our national purpose to provide equality through the improvement of opportunity for all, without regard to race, creed, or color. To this end, we have made education history in tackling the "first work of our society" by strengthening and improving the quality and educational opportunities with the Elementary and Secondary Education Act of 1965.

In the field of welfare we are recognizing that human needs must be met on an adequate base. For example, we are moving forward to build a new, firm floor in such programs as Aid to Families of Dependent Children, so that no child gets lost in the cracks of the present sagging structure which so frequently permits allowances inadequate for the basic healthy social growth of this important segment of our population.

We are seeking to establish new rates for the care of foster children who must live away from their natural homes so that--for those children whose future depends on benefiting from this form of care--there will be no deprivation, no sense of disadvantage, in the atmosphere in which they grow.

We are working to eliminate the disadvantage brought about by social change by intensifying manyfold our efforts to provide adequate day care for the children whose mothers work in ever-increasing numbers.

This acceptance of the need to meet social change with whatever innovation may be necessary was given additional meaning by Vice President Hubert Humphrey last month when he addressed a National Conference on Day Care Services. He said:

> "Day care is not a limited concept; it is not just for low-income families and working mothers. It is for the child who needs it, when and where he needs it and for the length of time he needs it."

Primarily, in the field of health, President Johnson has given explicit recognition of "the great and growing needs among our children for better health services" in his Health Message to the Congress of January 7, 1965. This recognition has now been translated into a bill, already passed by the House of Representatives, which offers the most significant advances in health programs since the passage of the Social Security Act.

These examples of national conviction are most heartening. The elimination of disadvantage is a goal worthy of our highest endeavors.

In the span of our national history, the concept of removing the disadvantage of mental retardation has come late but, as we all can be truly thankful, it has finally come.

And so I can speak to you now with an eye to the future, and the brighter prospects which lie ahead to minimize or erase the disadvantage for the special group with which we are concerned here--the mentally retarded.

For I view it as truly phenomenal that, once we have accepted

this brighter, more hopeful concept, so much progress has been made in so many diverse ways in such a short time span, particularly in aid of the retarded child and his family.

There has been a happy association between substantive legislation sponsored by many branches of government, action programs stemming from both public and voluntary sources, and a mounting research effort.

The most significant legislation, of course, was that which was initiated when President Kennedy appointed a Panel on Mental Retardation to discuss mental retardation in its broadest aspects with literally thousands of people in this country and abroad. Over 90 recommendations for action emerged in its report. They led, in 1963, to the Maternal and Child Health and Mental Retardation Planning Amendments. You have spent the last 2 days working with public health leaders and others on the State level approaches to the use of these planning grants. In an effort to get at causation, the 1963 Amendments also authorized an appropriation, to be administered by the Children's Bureau, to help State and local health departments provide programs of comprehensive maternity and infant care for women who have conditions associated with pregnancy which increase the hazards of childbearing for themselves and for their infants.

This comprehensive program is aimed at helping vulnerable women with a high incidence of complications of pregnancy, who deliver prematurely two or three times as frequently as the average for the nation.

It was launched with the knowledge that for the premature baby, the risk of mental retardation is increased twenty-fold.

There are, only 2 years later, some 21 maternity and infant care projects underway in the continental United States and Puerto Rico. The Children's Bureau is reviewing additional comprehensive plans from many other parts of the country which also are applying for this kind of preventive health program for mothers and children.

Through the projects already started, we have made progress in increasing the number of prenatal and postnatal clinics. There has been some relief of overcrowding in tax supported hospitals. Women who, up to this time, had been discharged from hospitals between 24 and 48 hours after giving birth to a child are receiving high quality medical care.

This is an important and exciting new facet of the Children's Bureau's programs in the field of mental retardation. But our special program effort goes back to 1956, when Congress, for the first time, earmarked $1,000,000 in our maternal and child health services appropriation specifically for services to the retarded.

There has been an immense step forward since then in the provision of diagnostic and treatment services for the mentally retarded. At the end of the calendar year 1964, the number of such clinics was 139, of which 94 were supported in whole or in part by maternal and child health or crippled children's funds.

These clinics are serving some 29,000 children, 11,000 of whom are new admissions. Significantly, about a third of the

children new to the program were under 5, which shows that our objective to reach young children is a practical one.

A particularly meaningful refinement in the early diagnosis of children who may become seriously retarded has come with the development, by Dr. Robert Guthrie, of a test to detect phenylketonuria in the newborn infant.

The Children's Bureau seized this opportunity to secure the cooperation of State and local health departments and hospitals in a mass screening of 400,000 infants within one year. The results of that survey are well known: The test was proved reliable for PKU and it also showed that the incidence of this metabolic disorder was twice as frequent as had been supposed. There has been incredibly rapid movement in putting this new knowledge to work. Some 2,600 hospitals in the United States are now using the PKU test. It is being carried out in 49 States plus the District of Columbia.

The Children's Bureau also played its part in this rapid escalation by making sure that the kit for one test was available at minimum cost--1.2 cents per baby instead of 40 times as much.

We are now using another test which Dr. Guthrie has developed to spotscreen infants for such other metabolic errors as histidenmia, galactosemia and maple syrup urine disease. The first case of an infant with this latter disease was found by the new method in a western city recently and the child was placed on a corrective diet. Here is another breakthrough which gives promise of significant progress in additional means of early detection of metabolic factors which may cause mental retardation.

A most promising area for further achievement in the field of prevention of mental retardation into which the Children's Bureau has moved since passage of the 1963 Amendments has been in funding of biochemical and cytogenetic laboratory services for assisting in the diagnosis of children and in genetic counseling of their parents. Thirteen such regional projects are currently underway.

We have every reason to hope that there will be additional projects in this field as we learn more about the role that inborn errors of metabolism and chromosomal abnormalities play as causes of mental retardation. This role certainly will become more apparent as research supplies us with new answers.

At the same time, we have been making advances on several fronts in services to retarded children through the state crippled children's programs. Of particular interest to members of this Association is the fact that we are now encouraging the expansion of our program of crippled children's services to those in institutions for the retarded who can be helped to become more capable of helping themselves. For too long these children have been at the bottom of the barrel in being provided services.

A recent study showed that if a single child could be relieved of physical impairments and learn to do such a simple thing as tie his own shoelaces, hours of the time of an attendant can be saved. Along with costs and savings achieved is the human savings in the feeling of achievement in the child which stimulates him to further success.

And so one of our major concerns in these crippled

children's programs is to provide an array of services to the mentally retarded child who is multiply handicapped.

Significant surgical advances are also being put to work under this program. For example, many States now are using new operative techniques which can be used to help hydrocephalic babies escape the ultimate brain damage which occurs with this condition and, at the same time, give these babies a chance to gain a normal appearance.

It has been said, and quite truthfully, I believe, that progress in recognizing the health needs of the retarded child has been vastly greater than the gains made in perceiving his welfare needs. The Children's Bureau is trying to even up the balance in the recognition of all the needs of the child through its partnership with the States in a program of child welfare services.

Here, the term "disadvantaged child" has added meaning when that child comes from families in the lower socio-economic status of society and may be suffering from psychological, social or cultural deprivation which may mask as retardation.

The Children's Bureau is trying to make the whole spectrum of child welfare services available to the child in his home to determine whether the child's problem is truly mental retardation or cultural deprivation. If the child is retarded, parents should have a choice between placing him in an institution and having the services available that make it possible for him to remain in the home. In one Florida project, family counseling has resulted in the fact that 60 percent of the families who had decided to place

their children in an institution, because of the services offered in the community by the project, were able to care for the child in his own home.

In North Carolina, a homemaker service project has helped families make arrangements for adequate care within the family group not only for a retarded child but for other normal children in the family group.

Day care, another important child welfare service, is being successfully used in many areas of the country to help retarded children not only gain social experience and intellectual stimulation but to relieve their mothers, as well, of the full-time burden of their care and of the tensions among their other children.

At the same time, several States are moving toward the development of coordinated programs between child welfare institutions for the retarded in order to make the most appropriate use of community and residential facilities based on the child's need. But we must face the fact that we need to make more progress than we have so far in developing adequate community facilities which will meet not only the diagnostic and health needs of the retarded child but his need for education, social services, group work, recreation, camping and day care.

From reports coming into the Bureau, we know that there are an increasing number of child welfare workers who already have a wide range of community contacts and community channels, knowledge of community attitudes toward the retarded, as well as knowledge of gaps in service and community capability for program development.

We believe these workers are in a key position and can be further stimulated to provide the kind of leadership which can spur communities on to develop coordinated programs of service which will meet all the needs of retarded children and their families.

The challenge in continuing meaningful research and putting it to work in new program concepts and action can only become reality when we face the equal challenge of securing enough adequately trained personnel to deal with all the facets of programs in aid of retarded children and their families.

The philosophy of the Bureau has been to expose large numbers of professional health personnel working with children to material on mental retardation, thus spreading knowledge as widely as possible.

But it is also pinpointing its efforts in many directions. During the current year, the Bureau is funding 27 pediatric fellowships in mental retardation, two additional in the fields of cytogenetics and biochemistry and is offering training to dentists and nurses either in clinic settings or as a part of curriculum in maternal and child care. Those nurses who have reached high degrees of skill in the care of the retarded in diagnostic centers are helping pass on their skills and knowledge to students in the health nursing field. From the very beginning of the Children's Bureau-supported mental retardation evaluation and diagnostic clinics, the education of social workers both at the graduate and post graduate level has been part of the program. The very nature of these clinics, with their multidisciplinary approach and their

careful evaluation of mentally retarded children makes them excellent field work placements for students in graduate schools of social work.

During the current year, some 44 social work students in field instruction are receiving all or part of their social service caseloads from mental retardation clinics.

Through field instruction, short term institutes, and every new method we can think of, therefore, we are encouraging in every possible way a larger pool of workers in both the health and welfare fields to make significant contributions to the lives of retarded children.

I have gone into this much detail on the ongoing operations of the Children's Bureau because I hope it not only gives you a clear picture of where we now are in relation to mental retardation, but may also activate the members of the American Association on Mental Deficiency to suggest to us new and useful approaches to meeting the problems we commonly face.

But our efforts are not confined to ongoing programs. Through the research and demonstration grants programs which now are a part of our maternal and child health, crippled children and child welfare services, we are encouraging institutions of higher learning and other non-profit organizations to undertake projects which may add new dimensions to the kinds of service we will be able to provide in the foreseeable future.

One such project is studying the feasibility of training of unskilled personnel as aides to professional personnel in caring for retarded children.

Another is a demonstration project which is testing out the most effective way of using group therapy for retarded adolescents.

Still another is studying how to maximize the value of homemaker service in the family which has a retarded child under five.

A long-range study is directed toward the many legal needs of mentally retarded individuals. The study is following the basic recommendations in the excellent section on legal needs in the report of the President's Panel on Mental Retardation.

We are helping to finance a project to see how feasible and valuable foster home care can be for a group of mentally retarded children whose retardation appears to be functional, perhaps partly due to adverse environmental experiences or parental inadequacies. We are measuring this program to explore many theories on this aspect of mental retardation.

Another project's aim is to work with girls living in highly urban areas develop group experiences which will help in their social development. This project includes but is not limited to the mentally retarded.

All of these projects are under the sponsorship of our child welfare research and demonstration program.

Just last week, before I left Washington, we received a report of a five-year study financed by the Bureau which gives us some new guidelines for future studies particularly directed toward the culturally deprived.

This study, conducted in Iowa by Dr. Robert Kugel and others, sought the answers to two basic questions:

What is cultural familial mental retardation?

How should cultural familial mental retardation be managed?

The study report, as is the custom with researchers, points out that the conclusions must be viewed with caution but suggests:

"By working diligently with...a group of individuals...when they are no older than 3 or 4 years of age, one may be able to ameliorate some of the pernicious factors so that these persons need not be condemned to life-long subnormality."

The study also suggests:

"That any effort to change the culturally deprived person must include an intensive effort at working with the total family, providing better housing, securing stable employment, improving health of all members of the family, and upgrading the educational experiences of the individual. Unless a total effort is supplied, it seems unlikely that this massive problem of our society can ever be managed let alone changed. One must also raise the question as to whether starting the efforts with these children at age 3 is not rather late. Perhaps even more intensive efforts to

reach the child soon after birth should be entertained."

These findings support our own belief that we must pay as much attention as possible to the child in his infancy, reaching him in these early formative years which have so much importance for his future development.

It seems to me that this study ties in neatly with another now underway which will try to uncover every case of mental retardation in a political subdivision in one eastern state to find out what etiological relationships exist between the prevalence of mental retardation and social, economic and demographic characteristics of the individual and his household.

I am bringing you all these examples of the accelerated programs of the Children's Bureau as possible points of departure during your Conference discussions as you cover the whole gamut of efforts on behalf of the retarded. There have been so many contributions in recent years, brought to the surface by public, voluntary agencies, as we have concentrated our attention on previously unexplored possibilities and I know that during the next few days in this Conference you will start with new zeal to broaden our horizons.

The Children's Bureau's interest in the health and welfare of children does not, of course, stop at our national borders, any more than does the concern of the American Association on Mental Deficiency in their international activities. We all have much to learn and much to give to other countries who are developing ways of serving individuals which might be applied here.

Like some other government agencies, the Bureau has in recent years had an opportunity to develop a research program related to child health services in some foreign countries, not paid for in dollars, but using the foreign currencies which the United States has accumulated from the sale of surplus commodities.

Since the projects we support must be of interest and value to the United States as well as to the cooperating foreign country, it is not surprising that mental retardation has absorbed a substantial part of these funds.

When the trial of the Guthrie technique for detection of PKU in newborns proved successful in the United States, we still had many unanswered questions, such as how widespread this condition is in various racial and ethnic groups. We proposed projects to test newborns and children in institutions in developing countries in which we had money for research. We made this proposal with some difference because PKU is certainly not a priority problem in a country which is only beginning to respond to the pressures of the many soc al, health and welfare needs.

Somewhat to our surprise, we met with enthusiastic response. Now we are supporting PKU testing programs in four countries--Poland, Yugoslavia, Israel and Pakistan--and have obtained some data from India as well.

It is very exciting to receive reports from these countries which are just discovering that they have cases and that they can prevent mental deficiency if they pick them up early enough.

If we are given more of these foreign currencies by the Congress this year--we have used up all we have--we plan to extend this program into other countries, Brazil and Egypt, perhaps, and

also carry out some other kinds of studies in mental retardation. This will reveal a comparison of factors of similarity in different ethnic, geographical or social settings to determine the constant.

Tonight, we can look backward to how far we have come in a relatively brief span of time in relation to improving the well-being of the retarded child. But we can also look forward, with full confidence and definite purpose, to making this record of progress a pilot of successful concentration on the needs of this handicapped group so it may stand as a symbol of what may be accomplished for other human needs. All of us who have a deep and abiding interest in the disadvantaged child can make the dream come true.

* * *